



## **Collecting Data**

The National Institutes of Health (NIH) must balance the need to maintain information about individuals with those individuals' rights to be protected against unwarranted invasions of privacy.

The Privacy Act of 1974, as amended, states that information collected must be relevant to the overall program objective and necessary to carry out an agency mission.

The goal of the Privacy Act is to directly solicit information from the individual. Why? **Accuracy!**

### **Mandatory Disclosure of Information**

For the most part, individuals provide NIH with their information on a voluntary basis. However, disclosure of private information is considered mandatory if an individual is required by law to provide the information AND is subject to penalty for refusing to provide it.

If a person chooses not to provide personal information, he or she must be informed of any consequences, such as not being selected for a study, not participating in a conference, or not being paid for services.

### **Privacy Act Notification Statement**

When directly soliciting personal information from an individual, you must provide them with a Privacy Act Notification Statement at the point of the information collection on manual and electronic forms and websites, and upon request.

A Privacy Act Notification Statement must include:

- The legal authority that allows the agency to collect the data (Government Statute, Public Law, Executive Order, etc.);
- The purpose of the collection;
- How the agency will use the information being collected;
- Whether providing the information is voluntary or mandatory; and
- The consequences, if any, for not providing the information.

### **Social Security Numbers**

The Privacy Act specifically addresses the collection and use of Social Security numbers (SSNs).

For example, you can collect an individual's SSN if the system of record you are using was in place prior to 1974. Otherwise, you cannot collect it unless federal law requires it.

By law, an individual's rights, benefits, and privileges cannot be denied due to an individual's refusal to provide a SSN, unless required by federal statute.

If the SSN or its last four digits are collected, the individual must be informed of the purpose and use of the information collection.

### **Children's Online Privacy Protection Act (COPPA)**

There are specific restrictions for websites that collect information from children under the age of thirteen. The COPPA requires verifiable parental consent **before** collecting personal information from children.